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ABSTRACT

In the fall of 1990, and again in the fall of 1991, George Washington University invited a parent of a special needs child to assist in the teaching of a course on the dynamics of family intervention. The rationale for this action was to: (1) give students a personal experience with a parent of a special needs child; and (2) provide a model of the parent-professional partnership. The course purpose and objectives were modified slightly from earlier years to reflect the new emphasis on partnerships between parents and professionals. Objectives of the course syllabus are listed, and several course readings are described. The relationship between the professional teacher and the parent evidenced challenges similar to those facing parents and professionals in other settings. In the fall 1990 semester, 8 students enrolled in the course; in the fall 1991 semester, 11 students enrolled. Interviews with students conducted after the completion of the course revealed their positive reaction to the parent's role in the course. Two bibliographic items are cited. Appended materials include copies of the interview questions with a sampling of students' responses, and a personal manifesto on the relationship between parents and professionals. (BC)

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# Transforming Student Perspectives Toward Families: Examples from Pre-Service Training

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The parent/professional relationship in early intervention occurs in a highly emotionally charged milieu. Families are often experiencing enormous stress due to the medical crisis experienced by their infants or toddlers and are faced with a uncertain future. The early intervention professional must be prepared to respond effectively to the emotional needs of families in order to assist the family in enhancing their child's developmental course. This requires empathy and objectivity. Simply put, the professional must be able to see things as the family member does.

Lazarus, Kanner, and Folkman (1980) in their classic essay on emotions state that, "...the beliefs or assumptions a person holds about himself or herself in the world determine the emotional response to daily events..."and that the clinical implication of this statement is that, "...if one changes what the person thinks and believes one can also change the pattern of emotional reactions to ordinary social transactions (p. 191). Students have emotional responses to families based upon beliefs or assumptions about their own families. Frequently, their exposure to theories of parenting or family systems is quite unsophisticated and without primary parenting experience of their own, many students would be unable to respond in any more than a superficial manner to the concerns of families. In addition, many individuals at the pre-service level lack the life experiences and self-knowledge that enables the mature professional to respond to complex interpersonal interactions. However, the "young" professional or student at the pre-service level may have a more fluid belief system that has not been reinforced by a career of nonfamily-centered practice.

This paper is based on the experiences of two university early intervention training programs related to the task of transforming the perspectives of students at the pre-service level toward families having infants with disabilities. Included is the description of one course that demonstrates that the adoption of a family perspective requires more than the acquisition of core knowledge and specific skills. The concept of transformation implies a qualitative shift in one's understanding and practice. In training, the observed integration of a belief system with core knowledge and skills signals the transformation of the student's perspective.



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Example 1

# Co-Teaching a Course on Families with a Parent of a Child with Special Needs

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## Introduction

In the summer of 1990, plans were made to invite a parent to co-teach Special Education 240: The Dynamics of Family Intervention: Theory and Practice at The George Washington University. The rationale for doing this was to 1) give students a personal experience with a parent of a child with special needs in a supportive learning environment, and 2) model the parent/professional partnership relationship desired in early intervention practice. This paper will describe the process of carrying out this relationship, the interaction of this relationship with the content of the course, and the direct and indirect effects on students related to having a parent in this role.

## Parent/Professional Partnerships as Best Practice

Since the passage of PL 99-457, early intervention has increasingly defined best practice as involving a strong parent/professional partnership. This concept of parent/professional partnerships is seen at multiple levels, including 1) in the development of the family's individualized family services plan, 2) service coordination (i.e., case management or care coordination) with some states training parent advocates to take on the responsibilities of this function with other parents and 3) policy-making with state agencies and in communities with parent representation on Interagency Coordinating Councils and Task Forces. With the growing emphasis on the parent's role in planning and providing early intervention services, it is important that early intervention personnel preparation programs offer future professionals opportunities to develop the skills to be full partners with parents in the provision of early intervention services.

## Course Background

Special Education 240, The Dynamics of Family Intervention Theory and Practice, has been a required course in the Master's Infant Educator program at The George Washington University for ten

years. The course has traditionally offered students a theoretical background in 1) the developmental process of parenting, 2) the particular stressors related to having a young child with a handicapping or at-risk condition, and 3) skills in communication needed to support families. The theoretical perspective of the course has been in the psychodynamic tradition rather than the behavioral tradition most commonly found in the field of special education.

Course Content

The course purpose, and objectives had to be modified slightly in order to reflect the new emphasis in the course on parent/professional partnerships. Language related to "respect for the collaborative relationship" was added to the course purpose and an objective related to the student acquiring the perspective of the parent of a child with a disability was added to the list of student outcomes.

The syllabus now contains the following course description: the purpose of this course is to present students with theoretical foundations and clinical techniques necessary for successful work with and support to parents of handicapped children. Instructional experiences are designed to bring students:

I. Knowledge of the theories and supporting research of:
   (a) family systems;
   (b) social support;
   (c) the developmental stages of parenting; and
   (d) stress and coping;

II. Skills in counseling needed to carry out special education or early intervention roles with families;

III. Respect for the collaborative relationship with family members that is needed to successfully carry out intervention techniques; and

IV. Awareness of the complex issues in support of multi-cultural, multi-ethnic and multi-linguistic families.

Supporting Readings

One of the readings for the course related to the theory of "Chronic Sorrow," had to be recast as a result of having a parent co-teach the course. The process of accepting a child's disability is sometimes presented in terms of stage-theory similar to the stages of grieving when there is a significant loss. Some have suggested that the concept of a stage of "acceptance" for a parent who has a child has a disability is inaccurate, rather that the parents experience on-going chronic sorrow related to loss as a result of the child's disability (Wikler, Wasow, & Hatfield, 1981).

However, some parents object to being considered to be chronically sorrowful. In this respect, the label of chronic sorrow can be stigmatizing. Labelling a parent as have accepted or not accepted their child's disability is also very misleading. In this instance, classic theories have to be cast in terms of the strengths and weaknesses of that theory.

The experience of loss as a central feature of human growth and development, however, remains a central concept in the course. Judith Viorst's Necessary Losses is one required reading that popularizes psychoanalytic theory of attachment, separation, and life-span development. Students are encouraged to see "loss" as a normal part of human growth; differences between families with children with disabilities and those without disabilities is a difference in degree of "loss" not in the kind of loss. Another theoretical perspective that incorporates loss as a part of growth and change was contained in readings about the developmental process of parenting by Ellen Galinsky.

Process

Modelling a parent/professional relationship in the university teaching setting has many of the same challenges that parent/professional relationships face in other settings. A central challenge relates to power and control. In this setting, as in any other, one person (i.e., the professional) has a certain amount of control and status that comes with the role. Inviting a parent advocate to co-teach a course opens the door for comparison on attributes that universities typically consider important. For example, what should the necessary degree be? How should payment for services be established? Who should decide what is in the syllabus?

We found that "flexibility" is critical and that there are no right answers to the questions in the paragraph above. Rather, just as in any parent/professional relationship, individuals are different and bring unique assets. While, the official faculty member wanted a great deal of input into the syllabus at the first planning meeting, it became clear that this was an unrealistic expectation. The parent advocate part of this teaching team had not taught a course before and did not want the responsibility for preparing a syllabus without having more experience in teaching. Instead, three class sessions were designated as being primarily the responsibility of the parent advocate. Very quickly, during the course, the parent advocate's role evolved and her contributions in terms of case studies or reactions to student remarks were a regular part of the class session.

Effects on Students

The syllabus states under objectives that:

Upon completion of the course, the student will have the ability to:

(1) Describe developmental functions and tasks of the family;

(2) Describe the developmental functions and tasks of parenting and the structure of families;

(3) Describe the extra stresses upon the family that persist when an at-risk/handicapped child is a member;

(4) Describe the multi-dimensional phenomena of "family dynamics";

(5) Identify and describe basic counseling principles as they relate to counseling the handicapped child and the family;

(6) Demonstrate communication techniques that inform and promote respectful, collaborative relationships with family members;

(7) Assess the needs of family members for community resources and make appropriate referrals to specific resources;

(8) Demonstrate understanding of the perspective of the parent of a child with a disability;

(9) Utilize self-knowledge as a tool to
(a) achieve empathy with family members;
(b) monitor one's own interactions with a family.

(10) Identify, describe and compare the informal and formal sources of social support.

There were 8 students in the Fall, 1990 course. One of these students was herself a parent of two children. All of the other students were women in their early to late 20's who did not have children. These students were interviewed at the end of the course. The range of responses to this interview are described in Table 1. The respondants were unanimous in their positive feedback regarding having a parent co-teach the course. The nature of the feedback was somewhat varied. Some students clearly felt empowered by the experience of being taught by a parent,

"You have also helped to reinforce that if you care enough and want something badly enough for a child, you can get it. I know I have and would fight for any family in need of care or services. You have shown us the way to do that constructively."

Based upon the over-all positive feedback, it was hoped that the co-teaching of this course would continue into the fall of 1991. Due to the difficulty of making a joint appointment without outside funds, the amount of time that the parent advocate could participate in the course was cut in half. We wondered if the shortened exposure to the parent advocate co-instructor negatively affected the student's experience. The parent advocate team member experienced the class quite differently because of the shorter exposure. The professional team member felt that the students continued to have gains from interaction with the parent advocate. As a team, we were able to function smoothly in spite of less "class" time together based upon having worked closely together in the previous year.

The students in the Fall, 1991 course numbered 11 and included three women who were also parents, one of whom was a parent of a child with a disability. Thus, even in the absence of the parent advocate, the parental point of view was quite apparent in all the class discussions. A short questionnaire was given to this group this fall to determine the effects of having a parent advocate co-teach the class and to gain a better handle on whether or not students were able to describe changes in their belief systems. All students cited positive advantages to having had a parent co-teach the class (See Table 2). Some of the processes related to their experience and changes in beliefs or assumptions is described in the following section.

Developing a Belief System

One of the early assignments in the course, asks students to develop a personal manifesto of the principles that would guide them in dealing positively with parents of infants with a disability, i.e.,

> "You have read much about the mistakes and assumptions professionals make in working with parents in this stage and about the needs of families at this time. As a parent-educator or early interventionist, state your personal manifesto of the principles that would guide you in dealing positively with parents at this stage. Cite and give a rationale for at least five principles."

The papers for this assignment generally followed the content areas suggested in the readings. As an early assignment, the paper provides a benchmark regarding the evolving beliefs and assumptions that a student holds. The identification of these beliefs and assumptions gives the instructor a baseline about possible avenues

to help students integrate new information that may challenge simplistic assumptions or beliefs. Generally, over time, each student's written assignments become more sophisticated.

When asked if their beliefs or assumptions had changed as a result of the course, three students said "no, they hadn't." These students were also parents. The students who had not had primary parenting experience all reported some change or acquired a difference in perspective. These are reported in Table 2. When asked to describe an "ah ha" moment, some students were able to be very descriptive about a moment when they viewed something differently. One student reported,

"In the discussion of IFSP's, when Ros said, "family centered" really meant family participation in the program as well as their choice not to participate."

Occasionally, a student took this early assignment very personally and presented a fully developed manifesto. Attachment A contains the personal manifesto of Bonnie Baugh, a student in the course. As a parent of a child with a disability, she brings a well developed sense of what parents need. On the other hand, as a parent involved in training to serve as a professional, the transformation challenge is directly related to her beliefs about professionals and their roles. Her manifesto describes her evolving perspective as a professional who knows family needs intimately.

Conclusions

The feedback from students uniformly indicates that having a parent co-teach a class on parenting and family issues is valued. The quality of student's written work and the richness of the class discussions also speaks to a positive interaction with a parent who can present the "parent perspective" first-hand. The responses delineated in Table 1 and Table 2 from the class participants demonstrates differences in ways that student's beliefs and assumptions were affected. This is most probably due to the fact that students come to the class with a unique set of beliefs and assumptions. They will change in different ways. And students with life experiences in parenting may change their beliefs or assumptions only minimally, if at all. The evolving sophistication of the younger students who had not had parenting experiences supports the view that these students are good candidates for training in early intervention.

We do not know if this type of training experience will have long-term effects and be carried with students into their professional careers. We hope that it does. We have only scant evidence at this point that it will. But this evidence is promising. About mid-September, 1991. three weeks into a new teaching position after graduating, a former student called and

asked for support in her efforts to assist families to challenge her school administrator's decision not to mainstream children with disabilities! She was counselled to sit back and let others take on this advocacy role -- that as a new staff member that she was vulnerable and had little influence. But she was fully supported in her instincts. Her professional views are a constellation of the parent perspective and all that she has learned to be best practice for children.

Note: Examples from Supervision in a second university setting will not be included in this poster presentation, but will be made available in another medium at a future time.

Appreciation is extended to Maxine Freund, Ed.D. for her substantial contributions to the Special Education 240 syllabus.

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TABLE 1

**THE DYNAMICS OF FAMILY INTERVENTION**
**THEORY AND PRACTICES**

**Fall Semester, 1990**

1. **How do you feel this course has enhanced your work with, understanding, and support of parents that have children with disabilities?**

   o Sensitized me to working with families. Made me think of issues I otherwise had not really considered or realized.

   o This course has provided me with some aspects of intervention strategies in dealing with families that I would not have have.

   o I feel this course has opened my eyes to the many approaches we must own when dealing with parents of children with exceptionalities. Just as their children have individual strengths and needs, it seems more apparent than ever before that the parents of these children do as well. We as professionals have to learn that every parent has specific needs no matter how similar their situation may be to another family.

2. **Has having a parent present in the course helped to change your attitude towards families of children with disabilities? How has it changed?**

   o It was nice to hear first hand from a parent. It made me more sensitive to the many feelings and concerns of a parent with a special needs child.

   o Having a parent as a co-teacher for this course gives a different perspective. It has made me more sensitive to the issues involved and concerns of family members.

   o Having a parent-professional present has been very helpful. You helped to show us that not every system is as it may look. Sometimes the people who are there to help needy parents are not aware of the whole picture and may wind up doing more harm than good.
   You have also helped to reinforce that if you care enough and want something badly enough for a child, you can get it.
   I know I have and would fight for any family in need of care or services. You have shown us the way to do that constructively.

3. **What do you feel you've learned so far about families' coping mechanisms. (How they deal with stressors?)**

   o The one thing I learned the most in terms of coping mechanisms is being sure the families have both formal and informal support to better help them deal.

   o Families have such varied reactions, I learned most of all that you have to be prepared for a wide range of reactions and responses and most of all, not to be judgmental or conclusive about the reactions/responses.

As far as families coping mechanisms, again they must be treated individually and accepted no matter how "different or abnormal" they may appear to be.
We also learned that what the reaction is on the surface may be different than the reaction from inside.
Again, we must look at the whole picture!

4. **Has this class in any way helped you to develop a better understanding about your attitude and approach to families of diverse cultural, social and economic backgrounds?**

   o This course has enlightened me as to a better approach in dealing with various families through being spontaneous. In other words, catering and gearing strategies specific to that family.

   Yes, again the key has been sensitizing us as interventionists to strengths, needs and concerns of the family. I would suggest again more case studies that would depict various cultural and ethnic backgrounds.

   Depending upon specifics such as socioeconomic background, exceptionality, etc., we again must approach each family as an individual case with individuals needs and expectations for their child.

5. **Is there something you wish we would have covered or something you feel you would still like to learn?**

   o One thing I would like to have spent more time on is IFSP process and development.

   o More counseling skills, i.e., videotapes of ways to give parents information or get information from parents in a sensitive, respectful manner.
   Techniques or suggestions in how to communicate at work with parents that may be defensive, hostile, resistant, etc.

Table 2

Student Responses
Fall, 1991

1. How have your beliefs about families (including your own family and families with and without children with disabilities) changed during this course?

Some families with children with disabilities are really strong in getting over the stress they have upon having this child and looking for a way to help him or her.

My views are more open to what makes a parent tick. I am better able to understand my own upbringing.

I am more sensitive to these children and their families. I try to learn more about all the children that I deal with who have disabilities. I feel it is important to learn about their families and their life outside school.

My beliefs have not changed, though I feel that I have gained insight into different family structures.

In general, all families are unique, with different structures and backgrounds. Traditional mother, father, child is not necessarily the typical family we work with today. We must take into consideration cultural differences.

I have gained experience by listening to parents talk about their family's coping strategies. Although I've done childcare for several years, it's a different experience from parenting. I've always known support is important, as well as communication, and that was re-iterated throughout.

2. Can you recall any specific reading, class experience or other moment when you had an "ah ha" or other revelation about families? If so, describe.

The readings on "stages of parenting" gave me a clearer perspective and understanding of why parents may react to or do certain things.

I thought Family Pictures was a wonderful book. The family's experiences were so real. It really made me think about how lucky I am.

Yes, more than one. The book, Necessary Losses hit on many points that I could relate to.

In the discussion of IFSP's, when Ros said, "family centered" really meant family participation in program as well as their choice not to participate.

3. What kinds of things have you learned from Ros Coleman about the experiences of families with a child having a disability?

It's hard work but very rewarding.

The most important thing that I have learned is about how to talk to parents and what not to say. Ros also talked about empathizing with parents, but not feeling sorry for them.

It can be frustrating getting the needs of your child met.

It is important to be sensitive to the parents concerning how much help they want, their intellectual level and cultural differences.

Personal input is always helpful and gives a firsthand experience view. I felt Roz was extremely effective.

They want someone to listen to what they have to say. To be honest and give them information. Most of all to be empathic and not sympathetic.

I've learned that you must be persistent if you want to get services for your child. You must begin to see yourself as an advocate, in addition to a parent. In a sense, you must come to the place where you realize that you will not obtain what you need until you ask.

Acceptance and understanding family difficulties became clearer through Ros as a resource. She was able to provide valuable information through her own experiences. She showed us how you can survive with support, resources, and pertinent information and to be positive.

4. What advantages and/or disadvantages do you see in having a parent co-lead this class?

She can relate her personal experiences with us. It is important to learn from personal experiences.

I think that there are many advantages. Most importantly was preparing myself for how to work with parents and be sensitive to the issues they are going through.

I don't see any disadvantage off hand unless the paent co-leading the class is focused only on his/her family experience and not open to others. I felt with Ros' personal and professional experience, she has been an asset to the class.

Professionals often speak from their observations of parents. Having a parent co-lead the class gives a personal view. It allows some of the emotion to be related to the students, thus making you more sensitive to the issues which surround parenting.

You are able to get first hand knowledge of what a parent must go through.

You are able to see their perspective when it comes to their view of the disability and the professionals who provide the service;

It helped to give you empathy for the situation of the parent and all of the variables involved in obtaining services/help for the family and child.

A parent helps to provide valuable information that you cannot learn through books. Personal experience gives light to another direction - what the process is really like, what strugggles and implications become obstacles, how you do survive with an exceptional child, and what course for success follows.

ATTACHMENT A

SPED 240
September 11
Personal Manifesto
Bonnie Baugh

I feel that providing true positive support for parents who are first learning about the condition of their disabled child is a process that begins long before the help is actually needed. It starts with my professional decision to enter this field and with the commitment, knowledge and openmindedness I bring with me. For, without the sincere desire to be of help in a time of great confusion and sadness, I might otherwise become another source of unhappiness for the family. I must be flexible, as illness and familial configurations vary, and I must be capable of exposing myself to the personal loss of others while maintaining my own emotional safety. My work must not become a chronic source of depression or breed a sense of helplessness or sadness that diminishes my professional skills. If this does occur, I must exercise the good judgement to take a rest or even change careers. A jaded, troubled professional in such a stress-filled arena is not a healthy alliance.

I must constantly sharpen my professional and intuitive skills so that I can answer questions knowledgeably, provide accurate information and detect the unspoken fears and concerns a family harbors. Information coming from the medical team, from readings and from experience will support my communication skills when the family wants to talk or when the questions begin. If I don't grow with my responsibilities then I deny my clients services they deserve. Likewise, I must be willing to to


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...t "I don't know" when I don't have the answers. It's better to say, "I'll speak with ..." or "I'll look that up ..." than to misrepresent my expertise.

I must let the family tell me, in general terms, how much help they need and how it should be delivered. I don't want to overwhelm them or neglect their needs; I want our relationship to develop as naturally as it can, given the circumstances. I want to be flexible in my style: if a family appreciates comic relief, I want to be comfortable smiling with them. If the family is withdrawn and feeling damaged, I want to coax and reassure them. Knowing when to start and stop and be quiet at these times is crucial to all involved.

I feel it's important that the professional team respect one another -- or at least give a unified front to the family. Casual remarks highlighting differences of opinion cause confusion and breed insecurity with clients at a time when they need to be stabilized. I'm not implying that professionals not be allowed to disagree; disagreements that intelligently discussed are often beneficial and enlightening. But when presenting these differences, I hope to give credence to the diverse thinking of my team -- not the Nemovesque eyebrow that causes the parental stomach to lurch! In essence, I want to gulp and smile if I disagree with another professional -- at least in front of my client. I'll talk with the other professional later and present my opinion privately.

I want to enjoy touching, both physically and emotionally, the lives of my clients. I want to rejoice in what an infant has

going FOR it, even if it has a dramatic birth abnormality or genetic disorder. At an appropriate time, it will be all right in the grief cycle to count blessings. As Rose Kennedy said about the deaths of several of her many children, "Birds sing after a storm, why not rejoice in what is left to us?" If my clients need a little more of me than I'm paid to give, I want to go that extra mile for them. Generally, the relationship that comes from a little extra nurturing does more good than harm. Also, I want to be sad with my clients if the sadness is genuine and warranted. Ultimately, I want to act like the guide to those lost in a dark cave -- helping find the safest path while looking for the light.

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